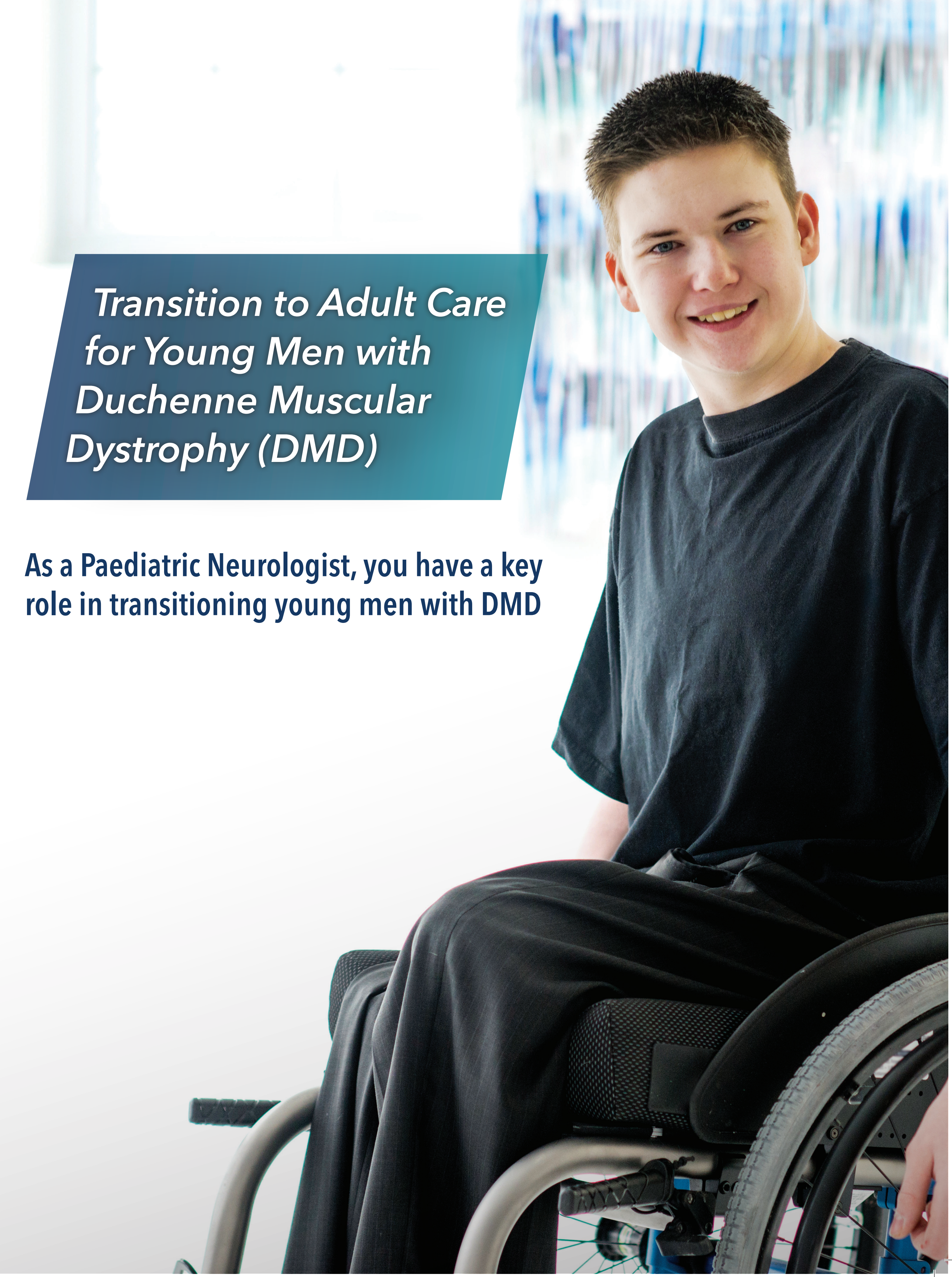


Transition to Adult Care for Young Men with Duchenne Muscular Dystrophy (DMD)

As a Paediatric Neurologist, you have a key role in transitioning young men with DMD

YOU ARE IN A UNIQUE POSITION TO HELP YOUNG MEN WITH DMD TRANSITION FROM PAEDIATRIC TO ADULT CARE

YOUR INVOLVEMENT IS CRITICAL

- The transition to adult DMD care is the process of transferring young adults with DMD from paediatric to adult-oriented healthcare[1,2]
- Patients' increasing involvement in managing their own care drives their need for education about the disease and support for the transition[3,4]
- Adult Neurologists need to understand DMD, their role in the transition process, and how to manage these patients[5,6]

CHALLENGES THAT MAY HINDER A SUCCESSFUL TRANSITION

YOUNG MEN WITH DMD

- Lack of understanding of the progression of DMD and the need for ongoing management and treatment[5,7]
- Desire for independence at the same time that increased intervention may be necessary due to disease progression[7]
- Difficulty leaving the Paediatric Neurologist and the paediatric setting (with established relationships and coordinated care)[3,6,8]
  - Lack of familiarity with the Adult Neurologist and the adult healthcare system
  - Fragmented multidisciplinary care with limited communication among adult care specialists
- Lack of preparation for new adult care responsibilities (as parents have been responsible for overseeing their children's care)[3]

ADULT NEUROLOGISTS

- Limited knowledge and experience in managing the complex needs of adults with DMD[6]
- Difficulty establishing a relationship with the patient due to time constraints[3]
- Limited coordination with other specialists involved in the patient's multidisciplinary care[6]

YOU CAN PROVIDE EXPERT KNOWLEDGE AND SUPPORT TO YOUNG MEN WITH DMD AND ADULT NEUROLOGISTS

- Your longstanding relationship with the patient and knowledge of DMD is essential for a successful transition[3,5,7]
- Educate the patient and the Adult Neurologist about DMD and the transition to adult care, explaining how and why the transition will occur[5,7,9]

AN IDEAL TRANSITION FROM PAEDIATRIC TO ADULT CARE

1 PREPARE/INFORM PATIENT

Paediatric Neurologist informs patient of transition to Adult Neurologist at least a year in advance[4,5,10,11]

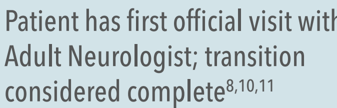
2 REFERRAL/ INTRODUCTION

Paediatric Neurologist introduces the case to Adult Neurologist and educates Adult Neurologist about DMD[10]

3 ADULT NEUROLOGIST/ PATIENT DISCUSSION

Adult Neurologist has introductory meeting with patient months in advance of official transfer of care to establish relationship[3,6]

4 FIRST PATIENT VISIT WITH ADULT NEUROLOGIST



Patient has first official visit with Adult Neurologist; transition considered complete[8,10,11]

5 SUBSEQUENT PATIENT VISITS WITH ADULT NEUROLOGIST

Patient and Adult Neurologist discuss goals, evaluate needs, and adjust medications if necessary[5,6,8]

TAKE THESE ACTIONS EARLY TO FACILITATE THE TRANSITION TO ADULT CARE

YOUNG MEN WITH DMD

- Communicate with patient at least a year in advance about when and how the transition will occur[4,10,11]
- Educate patient about DMD, its progression, and how to manage the condition[5,12]
- Identify patient's long-term healthcare needs, expectations, and goals[5,7]
- Document patient's progress toward adult care and living[4,10,11]
- Help to schedule introductory meeting for patient with Adult Neurologist[3,6]

ADULT NEUROLOGISTS

- Prepare the Adult Neurologist by sharing information and resources about DMD, the transition process, and adult patient management[7-9]
- Provide full history of the patient case[10,11]
- Introduce the Adult Neurologist to the patient[10]
- Consult with the Adult Neurologist as needed about the particular case[8,11]

SUCCESSFUL TRANSITION PLANNING PREPARES AND EDUCATES BOTH THE PATIENT AND ADULT NEUROLOGIST

GUIDE THE YOUNG MAN WITH DMD AND EDUCATE THE ADULT NEUROLOGIST TO ENSURE A SUCCESSFUL TRANSFER OF CARE

CHECKLIST OF ACTION ITEMS FOR PAEDIATRIC NEUROLOGISTS AT EACH KEY STAGE OF THE TRANSITION PROCESS

1 PREPARE/INFORM PATIENT

Prepare and inform patient of transition to Adult Neurologist at least a year in advance[4,5,10]

- ☐ Inform the patient prior to the transfer to adult care[4,5,10]
- ☐ Educate the patient about the transition (eg, why it needs to occur and for how long it will occur) and managing DMD as an adult (eg, how the condition will continue to progress)[5,12]
- ☐ Give the patient the **Patient Transition Toolkit**, which includes:
  - **DMD Overview for Patients**
  - **DMD Adult Care Transition Guide for Patients**

2 REFERRAL/INTRODUCTION

Introduce case to Adult Neurologist and educate Adult Neurologist about DMD[4,8-10]

- ☐ Send **Transitioning Patient Form Letter** and **DMD Patient Medical Summary** to the Adult Neurologist
- ☐ Share with the Adult Neurologist the **Adult Neurologist Toolkit**, which includes:
  - **DMD Transition Checklist for Adult Neurologists**
  - **DMD Overview for Adult Neurologists**
  - article on **DMD Consensus Care Guidelines**
- ☐ Complete and send to the Adult Neurologist other materials that you consider appropriate, which may include[10,11]
  - ☐ Final transition readiness assessment
  - ☐ Additional clinical records and legal documents as needed
  - ☐ Patient management and DMD treatment materials
- ☐ Reach out to Adult Neurologist to answer questions about DMD, its management, and patient history months in advance of patient's first visit[7-9]
- ☐ Discuss details of patient case with Adult Neurologist[10,11]

3 ADULT NEUROLOGIST/PATIENT DISCUSSION

Adult Neurologist meets with patient months in advance of first official visit to establish relationship[3,6]

- ☐ Help to schedule meeting (held months before first official visit) to allow for conversation and relationship building[3,6]

4 FIRST PATIENT VISIT WITH ADULT NEUROLOGIST

Patient has first official visit with Adult Neurologist a few weeks after introductory meeting; transition considered complete[8,10,11]

- ☐ Confirm completion of transition with adult practice[10,11]

5 SUBSEQUENT PATIENT VISITS WITH ADULT NEUROLOGIST

Patient and Adult Neurologist continue to discuss goals, evaluate needs, and adjust medications if necessary[5,6,8]

- ☐ Contact patient 3 to 6 months after last paediatric visit to confirm attendance at first visit[11]
- ☐ Offer ongoing consultation assistance to Adult Neurologist as needed[11]

As a Paediatric Neurologist

Your knowledge and support are critical to help young men with DMD transition successfully to adult care

YOUR ACTIVE INVOLVEMENT CAN HELP ENSURE A POSITIVE TRANSITION EXPERIENCE

- Start the transition process early, at least a year in advance of the patient's first meeting with an Adult Neurologist[4,10,11]
- Educate the patient on DMD and what to expect when transitioning to adult care[5,7,9,12]
- Share your knowledge, experience, and resources with the Adult Neurologist[7-9]
  - Educate them on the complex needs of adults with DMD and the transition process

References: 1. Onofri A et al. Ital J Pediatr. 2019;45(1):90. **2.** Blum RW et al. J Adolesc Health. 1993;14(7):570–576. **3.** Varty M et al. J Pediatr Nurs. 2020;55:201–210. **4.** Trout CJ et al. Pediatrics. 2018;142(Suppl 2):S110–S117. **5.** Birnkrant DJ et al. Lancet Neurol. 2018;17(5):445–455. **6.** Quinlivan R et al. J Neuromuscul Dis. 2021;8(6):899–926. **7.** Wasilewska E et al. Medicina (Kaunas). 2020;56(9):426. **8.** White PH et al. Pediatrics. 2018;142(5):e20182587. **9.** Lindsay S et al. Disabil Health J. 2017;10(1):73–79. **10.** Six Core Elements of Health Transition™ 3.0: an implementation guide. Got Transition. Revised July 2020. Accessed 28 April 2022. https://www.gottransition.org/6ce/?leaving-ImplGuide-full **11.** Six Core Elements of Health Transition™ 3.0: side-by-side comparison. Got Transition. Accessed 28 April 2022. **12.** Ambrosini A et al. Orphanet J Rare Dis. 2019;14(1):126.

This material has been developed and funded by PTC Therapeutics. It is intended for healthcare professionals only.
Date of preparation: May 2022 | GL-DMD-0522